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ABSTRACT

The report investigates the medical background and circumstances surrounding the death of a severely retarded adult male who was a resident of a community developmental center in New York State. It illustrates the complex medical, legal, and ethical issues involved in medical decision making on behalf of persons unable to provide informed consent. The report chronicles the patient's institutional history, the medical treatment he received at two different hospitals outside the developmental center, communication with a family member, postoperative condition and treatment, and autopsy results. A mental hygiene medical review board concluded that the condition of the patient while in residence at the community facility deteriorated significantly over the course of a few years. Decisions involving consent for major medical procedures were also questioned. Among seven review board recommendations were the following: (1) the Office of Mental Retardation and Developmental Disabilities should clarify, through specific policy statements and guidelines, who should be consulted with respect to medical care decisions on behalf of an incompetent client; (2) the community developmental center should evaluate its treatment planning process to assure that periodic multidisciplinary treatment reviews address all client needs and assess any observed changes in clients. (JW)

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In the Matter Of Joseph Kirsh

A Resident of Craig Developmental Center

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A REPORT

BY THE NEW YORK STATE COMMISSION ON QUALITY OF CARE FOR THE MENTALLY DISABLED AND THE MENTAL HYGIENE MEDICAL REVIEW BOARD

EC 200 556

Clarence J. Sundram
CHAIRMAN

Irene L. Platt
James A. Cashen
COMMISSIONERS

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February, 1987

PREFACE

This investigation focused on the circumstances surrounding the death of Joseph Kirsh,* a resident of Craig Developmental Center who died at Genesee Hospital.

Our investigation underscored the need for clearer directions and guidelines for medical personnel to help them in making care and treatment decisions relative to incompetent mentally disabled persons who are without legally recognized surrogate decision-makers. This need for guidance is intensified because of the increasing emphasis on providing medical and surgical care and treatment in community hospital facilities rather than in medical units of developmental centers. In these community hospitals, the treating physician(s) immediately responsible for the care and treatment of mentally disabled patients are usually private practitioners who are unaccustomed to the regulations and medical guidelines of the State-operated facility where the patient has been residing.

The Commission investigation also indicates, we believe, the need for OMRDD to clarify its regulations, policies and procedures regarding who has the right to consent to non-emergency major medical procedures proposed to be provided to incompetent clients.

This report illustrates and recognizes the many difficult medical-legal-ethical issues and concerns raised when essential

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*A pseudonym.

medical-surgical decisions are made relative to the treatment of persons who are unable themselves to provide informed consent. Some of these issues have been and are being addressed through the work of the Governor's Task Force on Life and the Law and are best addressed by legislation or by court decisions. In addressing them, the Commission suggests that some guidance might be found in the provisions of the recent 1984 Amendments to the Child Abuse Prevention and Treatment Act.

These Amendments, in applicable part, deal with the "withholding of medically indicated treatment" to disabled infants under certain specified circumstances. Under these provisions, the withholding of such treatment to disabled infants other than "appropriate nutrition, hydration, and medication" is permissible when in the treating physician's reasonable medical judgment

(A) the infant is chronically and irreversibly comatose;

(B) the provision of such treatment would (i) merely prolong dying, (ii) not be effective in ameliorating or correcting all of the infant's life-threatening conditions; or (iii) otherwise be futile in terms of the survival of the infant; or

(C) the provision of such treatment would be virtually futile in terms of survival of the infant and the treatment itself under such circumstances would be inhumane.

Relatedly, the 1984 Amendments to the Child Abuse Prevention and Treatment Act, referred to above, also require that states, participating through grants under the Act, establish

a procedure to respond to the reporting of medical neglect, including the withholding of medically-indicated treatment, which procedure must encompass authority for the state child protective services system to pursue legal remedies. The Amendments recognize the need for an independent advocate for the disabled infant and require the appointment of a guardian ad litem in any judicial proceedings.

The contents of this report have been shared with the Office of Mental Retardation and Developmental Disabilities, the Director of Craig Developmental Center, the Administrator of Bethesda Hospital, the Administrator of Genesee Hospital and the Director of the Mental Hygiene Legal Service, Fourth Judicial Department.

Findings, conclusions, and recommendations set forth in the report represent the unanimous opinion of the members of the Commission and the Mental Hygiene Medical Review Board.

Clarence J. Sundram
Chairman

Irene L. Platt
Commissioner

James A. Cashen
Commissioner

METHODOLOGY

In conducting this investigation of the death of Joseph Kirsh,* the Commission and the Mental Hygiene Medical Review Board reviewed the clinical records of Craig Developmental Center, Bethesda Hospital and Genesee Hospital, as well as the findings of the Mortality Review Committee of Craig Developmental Center and the autopsy report. Site visits were made and interviews were conducted with staff and administrators of Craig Developmental Center, Bethesda Hospital and Genesee Hospital.

A draft of this report was provided to all parties. The final report reflects written comments received and comments made at a meeting held with representatives of Craig Developmental Center, the Office of Mental Retardation and Developmental Disabilities, and the Mental Hygiene Legal Services.**

BACKGROUND

Joseph Kirsh was born on October 17, 1937 in Queens, New York. At the age of two, Joseph fell 20 feet from a window and sustained a fractured skull and left-sided paralysis. Although able to start school at six and one-half years of age, he was subject to temper tantrums and, at approximately age 10, had his first grand mal seizure.

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*A pseudonym.

**Until April of 1986, known as the Mental Health Information Services.

At age twelve, Joseph Kirsh was admitted to Craig Developmental Center, then known as Craig Colony, a State Institution for Epileptics. At that time his admission diagnosis was moderate mental retardation and he was able to totally care for his personal needs. His behavior was noted to be "fairly good" and he was described as well-oriented and well-nourished. Medication successfully controlled his seizures.

According to psychological tests performed in 1949 at age 12, he had an IQ of 52 (moderate range of retardation); in 1951 at age 14, his IQ was 56; and in 1973 at age 36, his IQ was 41.

In early adulthood, he was between 5 feet 8 inches and 5 feet 10 inches tall (varied on different records), averaged about 150 pounds and was fully able to care for himself.

However, by 1976 Mr. Kirsh, at age 40, had deteriorated into a "bed to chair" resident. A 1976 psychological evaluation described a gradual regression but also noted that Mr. Kirsh was verbal, articulate, could read and write and perform simple math exercises. The psychological records stated: "the degree of Joseph's helplessness as described in recent records appears highly exaggerated," and also noted that Mr. Kirsh complained of the absence of visitors, lack of tasty food and lack of programming, and expressed a wish to return to his former

job in the laundry. When asked why he no longer was walking, the record states "he whined, I'm paralyzed; I can't walk anymore." The patient, according to the psychologist, was showing signs of organic brain syndrome with a passive-dependent personality. Psychological evaluations in 1978 suggested a need for physical therapy, "training and stimulation." It was reported that Mr. Kirsh was functioning below potential, and it was observed that food and social praise would be good positive reinforcers. Even though these psychological tests appeared quite comprehensive, there was no documented follow-through of the psychologist's recommendations in Mr. Kirsh's day-to-day care at Craig Developmental Center.

The records indicate Joseph Kirsh developed a decubitus ulcer on his left hip and ankle in 1978 and that an ultra violet lamp was used for treatment. Whirlpool baths were used in September 1979 and passive range of motion therapy in March 1980, but these were discontinued from May to December 1980 with no recorded rationale.

In July 1980, the results of another psychological test concluded that there was a "stark contrast" to the previous test results; it noted: "he is bedridden and has multiple bedsores...and chronic hiccoughs" and "he seems quite debilitated." The psychologist's note remarked that two years earlier Mr. Kirsh had an IQ of 52, "but now, at age 43, for unknown reasons, he can barely be tested. For

statistical purposes, an IQ of 20 is assigned." There is no notation in the record that any other clinician was aware of this conclusion by the psychologist, nor that any further testing was done to determine the possible cause of this change.

By mid-1980 the patient's decubitus ulcers had become so much worse that he was seen in the surgical clinic for consideration of possible surgical treatment. In September 1980 surgical consultant Dr. Chin,* wrote that the ulcerations "should be grafted." In November 1980, Dr. Chin recorded "please obtain operation permit for split thickness skin grafting." There is, however, no further mention of performing this procedure in the record and, apparently, the patient was neither seen again by Dr. Chin, nor was the surgery performed by anyone else.

Three months later, in February 1981, Mr. Kirsh was treated at Bethesda Community Hospital for hemorrhagic esophagitis (bleeding of the esophagus) and was prescribed Gaviscon and Tagament. A Bethesda Hospital surgeon, Dr. McCarthy,* also evaluated Mr. Kirsh's decubitus ulcers at that time. In May 1981, Mr. Kirsh was again seen by Dr. McCarthy, who recorded:

> 43 year old male patient referred at this time for evaluation of a decubitus ulcer left hip and left foot. Question of skin grafting. History of this patient is well known to me and had been

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*A pseudonym.

> evaluated approximately two to three months ago at Bethesda Hospital for GI bleeding. With respect to the problem of decubiti, the large decubitus over the greater trochanter of the left hip has been present for years and while it is now very clean and granulating well, physical examination reveals that the area is much too large and much too mobile for a simple split thickness skin grafting.
>
> RECOMMENDATIONS: For treatment if it is indicated in this situation is removal of the greater trochanter itself and then pedicle or swinging flaps to overlie the area and close it primarily. This is beyond my expertise and would require the assistance of both an orthopedic and plastic reconstructive surgeon; and if this decubitus becomes a problem or if he feels strongly about closure of the area, then I would refer him perhaps to Strong Memorial Service, Plastic Reconstructive and/or Orthopedic Clinics.

There are no follow-up comments by Craig staff contained in the patient's record in response to this recommendation, and the extent and condition of the ulcerations are not adequately described by Craig physicians.

In July 1981, Mr. Kirsh was transferred to the medical unit (then referred to as "Peterson Hospital") at Craig, due to fever and anemia. He remained there for ten months suffering further physical deterioration, yet there are no indications in the record during this time that any efforts were made to determine the cause of this regression. He was described in Peterson records as essentially immobile with marked flexion contractures, and the decubitus ulcers became deeper and more severe.

Craig Developmental Center's description of these ulcerations was consistently scant. In September 1982,

when Mr. Kirsh spent ten days at Strong Memorial Hospital (SMH), medical staff there recorded "chronic decubiti with bilateral pelvic ulcers." A plastic surgery consult noted: the lesions were "granulating nicely" but that the patient was not a candidate for graft or flap formation. SMH physicians recommended local care with Betadine wet to dry dressings, heat lamp treatment three times a day, whirlpool treatments every other day, a water bed mattress, sheep skin on the bed and dietary supplement of Ensure. Several of these recommendations were followed when Mr. Kirsch returned to Craig, and the ulcers continued to heal.

TREATMENT AT BETHESDA HOSPITAL

On January 24, 1983, Mr. Kirsh was readmitted to the medical unit at Craig Developmental Center due to dehydration and anemia. In response to his need for hospital level care, on January 26, 1983, he was transferred to Bethesda Hospital in Hornell, New York and remained there until March 15, 1983. The following chronicles his time there:

January 26, 1983: A transfer note by a Craig Developmental Center physician indicated the chief reason for transfer was gastrointestinal bleeding. It also observed that the patient's decubitus ulcers were chronic and in the "healing stage." When he was admitted to Bethesda Hospital, physicians there concurred with the diagnosis of an upper gastrointestinal hemorrhage, and his stool tested positively for blood.

The admission nursing assessment form at Bethesda Hospital, completed at noon on the day of admission, states: "noted several open decubiti on hips and feet of badly contracted body." An admission note by a nurse states: "both hips open with red fleshy areas. Areas appear clean."

January 28, 1983: An endoscopy* was attempted three times, in an effort to locate the source of the bleeding, but could not be done, because of the patient's inability to cooperate with the procedure. The Craig Developmental Center administrator on duty gave telephone permission to perform the endoscopic procedure.

January 30, 1983: The patient's decubitus ulcers were described on this day as "oozing frank pus."

February 2, 1983: The ulcerations were described as being necrotic.

February 3, 1983: The right hip was noted as having "bloody serous drainage" and "the odor of pseudomonas." Mr. Kirsh's temperature was 102°F.

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*An endoscopy is the inspection of the upper gastrointestinal tract by insertion of an endoscope through the oropharynx and down into the esophagus. The endoscope is a tube and optical system for observing the inside of an organ or cavity.

February 9, 1983: Dr. Taylor,* a medical doctor at Bethesda Hospital, noted in the patient's record that he would consult with Dr. McCarthy,** a surgeon, for suggestions regarding the ulcerations which he observed were worsening.

February 11, 1983: Dr. McCarthy saw the patient and wrote a lengthy evaluation noting:

> This is a very sad case. There is little I have to offer surgically in the way of reconstruction but I will be happy to try to oversee debridement of these multiple decubiti.
>
> As to definitive grafting or turning of flaps to cover these areas, I think that this is probably not only inappropriate in this patient, but also will be extremely nonproductive in that patient cannot ever expect to be rid of his contractures and even with the excellent care at Craig Developmental Center, the decubiti and any grafts that are placed over them are doomed to failure.
>
> This is my personal opinion, but it hopefully is a realistic one and at this point I would be conservatively aggressive on debriding the decubiti, but as far as any coverage, I think that this would not be possible in this patient.

Dr. McCarthy offered the following recommendations: egg crate mattress, increased protein in his diet in order to promote healing, and the use of supplementary feedings; such as Ensure. According to the record, these recommendations were implemented by Bethesda Hospital, and the patient is often described as consuming extra Ensure.

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*A pseudonym.

**The same surgeon who had seen Joseph Kirsh in 1981 during the prior hospital stay at Bethesda.

February 13, 1983: Dr. Taylor ordered that administration of antibiotics be discontinued the following day.

February 15, 1983: Mr. Kirsh remained feverish and Dr. Taylor wrote: "as suspected, patient now has pneumonic process by chest x-ray." Dr. Taylor also noted that he had discontinued antibiotics on the previous day and had, on this date, taken a sample of the patient's sputum for a culture. Dr. Taylor noted "...will wait to see what cultures show before restarting antibiotics."

February 17, 1983: Dr. Taylor wrote: "...temperature 102° ...more lethargic...oral intake was down yesterday... sputum growing Gram negative bacteria...will attempt to talk with patient's sister to explain current poor prognosis."

February 18, 1983: Dr. Taylor further identified the organisms grown on culture, and noted "will attempt to treat orally." Nurses' notes indicate the patient was put on a cooling blanket on this date and a "do not resuscitate" telephone order (emphasis added) was given by Dr. Taylor and noted in the record. A nurse's note indicated the patient was taking oral fluids well and drank 8 ounces of Ensure. The patient resumed taking an oral antibiotic, as well as his Phenobarbital and Dilantin, Tagament, Reglan, Gaviscon Mylanta, vitamins, folic acid, and Effer-syllium.

February 19, 1983: Dr. Taylor recorded a conversation with the patient's sister as follows: "spoke with patient's

sister and she wishes no further aggressive treatment at this point. She is contacting patient's brother but feels he will wish the same thing. We will continue to attempt to give him antibiotics by mouth but I will not start IV (intravenous)." A nurse recorded "tolerated diet well. Ensure plus with ice cream taken well."

February 21, 1983: Dr. Taylor's record entry included:

> ...still taking orally very well; does not seem to be in distress except when turned in bed. We have to continue with current palliative measures.

February 27, 1983: The patient continued to take oral liquids and oral medications well. It was noted that he was eating pureed foods, and was lifted out of bed and spent time sitting in a chair each day.

February 28, 1983: Dr. Taylor noted that another x-ray of the lungs showed "clearing," and that the patient's highest temperature was only 100.6°. He recorded "if we can get his temp to remain normal for a few days, could consider transfer to Craig."

A nurses' note on this day describes a telephone call she received from the patient's sister. The nurse stated that the sister said "I want no CPR, no support systems, but I do want him kept comfortable."

CONTROVERSY OVER BETHESDA HOSPITAL CARE

In a letter to Craig administrators, received on February 28, 1983, Dr. Taylor stated that he had discussed the care of Joseph Kirsh with the patient's sister and it had been decided that palliative (comfort) care would be provided. In fact, at this time, Bethesda Hospital was giving the patient food, nourishment, oral antibiotics, and other medications, as well as treating the decubitus ulcers each day.

Dr. Taylor's letter stated, in part, that:

> We will continue to give him palliative therapy with cooling blanket if necessary to keep his temperature in control, but no further aggressive therapy will be administered for any serious bacterial infections.

When the letter was shown to the Craig Developmental Center Deputy Director on February 28, 1983, he immediately contacted OMRDD Counsel's Office and held discussions with the Deputy Director of Health Services and the Director of Craig Developmental Center regarding the letter's content. It was decided to demand of the treating physicians either more aggressive medical treatment for Joseph Kirsh, or that he be transferred to another hospital.

Memoranda to the files from the Deputy Director of Craig Developmental Center indicated that he was unable to contact Dr. Taylor, but did speak to Dr. Parvey* on the

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*A pseudonym. A physician associate of Dr. Taylor.

evening of February 28. Dr. Parvey was told by the Craig administrator that it was the wish of the facility that "aggressive treatment and care be given" to Joseph Kirsh. Dr. Parvey said he would see the patient, discuss the case with the nurses and reestablish more aggressive treatment. He requested a follow-up letter from Craig stating "aggressive care be given." The Craig administrator also told Dr. Parvey that the authority to make medical decisions concerning the patient's care did not belong to the patient's sister.

In another note to the file, the Deputy Director stated that on March 1, 1983 he spoke with Dr. Henry* on the telephone and noted:

> he seemed quite distressed with our request which went contrary to the decision made by the sister of the patient. He requested that we respond in writing to the following question: 'What is the role of the family and who has veto power over the family?'

The Deputy Director's memorandum also indicated he told Dr. Henry that Craig Developmental Center had the responsibility and authority regarding care and treatment of clients, "in keeping with our perceptions of a client's needs," and he noted the needs in this case "having been defined...by the Deputy Director of Health Services."

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*A pseudonym. Another associate of Dr. Taylor, who apparently informed the Deputy director that he, not Dr. Parvey, was responsible for Joseph Kirsh's care in Dr. Taylor's absence.

The Deputy Director of Craig Developmental Center also noted that, later on March 1, he had another telephone conversation with Dr. Parvey in which the State policy as to CPR was discussed. The Deputy Director's memo indicates Dr. Parvey said that he would not allow State policy to "interfere" with their (Bethesda physicians) clinical, professional policies. In his memorandum, the Deputy Director wrote that Dr. Parvey's opinion was "CPR would be crazy with this man. He is in fetal position."

According to the Deputy Director's record, when he first spoke with Dr. Parvey, the doctor requested to know "who the next-of-kin was." The Deputy Director wrote "I indicated that in this case I was not sure what next-of-kin meant, but the Director of this agency was charged with the responsibility of care."

The Deputy Director's file notes also indicated that he and the Deputy Director for Health Services had spoken to Mr. Kirsh's sister who acknowledged she "concurred with Dr. Taylor that no life support systems" be used to maintain the life of her brother. The Deputy Director recorded that he told the sister, "you were not discussing life support systems but antibiotic therapy."

He noted that the sister's overall response was:

> 'If within a year they find a cure for what's wrong with him and he can come home and be a real brother, okay. If not, he should be allowed to go as a result of what is wrong with him.' I stated that I understood her view but that we could

> support nothing less than aggressive treatment and care on behalf of each and every one of our clients.

In Dr. Parvey's written record of his conversation with the Deputy Director of Craig Developmental Center on February 28, 1983, he notes that the Deputy Director "legally directed our facility to provide comprehensive care and believes that only Craig Developmental Center is legally responsible for Mr. Kirsh." Dr. Parvey then described Mr. Kirsch's condition:

> ...very emaciated, mentally unclear although he is able to respond to verbal stimulation now and then; large decubiti are present over the buttock areas, exposing a good part of the periosteum (bone) and covered by poor granulation tissue and additional decubiti are present around the feet. Patient has assumed a fetal position with flexion contractures, total body deformity and seems to have moderate pulmonary congestion.

Dr. Parvey concluded: "I do not see any objection in the use of IV fluids and antibiotics pending repeat culture studies. The care of this patient will be turned over to Dr. Taylor upon his return." Dr. Parvey then contacted Mr. Kirsh's sister in New York City and explained the situation to her. She agreed to resumption of the IV fluids and antibiotics, but requested that no mechanical ventilation or cardiopulmonary resuscitation be used. Dr. Parvey concurred with this, as noted in his written statement:

> In view of the moribund nature of the patient and the medical contraindications for CPR, namely

> total body flexion deformities, and the lack of adequate brain functions, I concur with her decision from the medical point of view.

An intravenous was begun and IV Kefzol, an antibiotic, was ordered.

On March 7, 1983: Dr. Taylor returned from vacation and charted:

> Continuing to drink well--continues to spike temps. Will review recent communication with Craig regarding patient's care.

The following day he noted "since we were not able to place peripheral IV, I will once again give him Septra suspension," (an oral antibiotic). "In my view, placement of a large line--ie: CVP--is more aggressive therapy with significant risks and I don't feel it is appropriate in this instance. If Craig does not agree with this, they are free to transfer the patient to an institution that feels it is so."

On March 11, 1983 Dr. Sanders,* a Craig Developmental Center physician who cared for Mr. Kirsh while at Craig, noted in a typed statement, dated March 16, 1983, that he received a phone call from the "Chief of Medical Services" (actually Deputy Director of Health Services) at Craig asking him to see what he could do about transferring Mr. Kirsh to Genesee Hospital. Dr. Sander's note continues:

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*A pseudonym.

I called Dr. Taylor at his office in Hornell to find out more about Joseph. When I got a hold of Dr. Taylor on the phone, he expressed his irritation of being called and told me that he does not want to discuss the case any further and that if I wanted further details, he would gladly write me a letter. I tried to be very diplomatic with him, and I told him that I wanted to let him know that our actions in the past few weeks were not in any way intented to slight him or to dictate to him how he should treat Joseph or any client for that matter coming from Craig Developmental Center. We just wanted him to continue treating Joseph. He then told me that he resents the fact that the State had stepped into the case after he already had spoken to Joseph's family and that they had agreed not to treat Joseph. He told me that this man had suffered a lot and that he should be let go. I replied to him that we at Craig are his advocates, and we do not think that the treatment he required was heroic and that we were not dealing with a person who was a vegetable in life support system. He then told me that if we feel that we are not happy with the way he is treating Joseph, we should find another physician in another facility to take care of him.

Then he said he refused to be interrogated on the management, and I told him that I am not interrogating him, that I just wanted to know the present medical condition of Joseph. I also told him that I hope he did not make this decision because Joseph is mentally retarded. He then said something and hung up on me.

Addendum to the conversation with Dr. Taylor. During the course of our conversation, he mentioned to me that he had a similar case one year ago of a client who had pneumonia and that he withheld therapy after conferring with the family and the client died a month later. He said that he had no trouble at that time. Why is he now having so much trouble with the State. He also said that the authorities at Craig do not have the right to harass and dictate to his partners how to treat Joseph. In addition, he will not start intravenous fluids or give intravenous antibiotic therapy or insert a CVP line or start hyperalimentation because of the

> risks involved. He did mention that Joseph is eating and drinking and that he is giving him Bactrim orally for the infection.*

Dr. Taylor also recorded his version of the "long and difficult conversation" with Dr. Sanders and noted that Dr. Sanders "accused me of withholding treatment because of Joseph's mental retardation. I once again reiterated to him that he is free to request transfer if he is not satisifed with my care. My office was notified that as soon as a bed opened at Genesee Hospital, Joseph was to be transferred. I agreed with this."

A comprehensive two-page typed transfer note was dictated by Dr. Taylor, which recounted the patient's medical history and the appearance of the decubitus ulcers. Dr. Taylor also related his conversation with the patient's sister, and noted that he withdrew antibiotics from the patient. He then wrote:

> ...shortly thereafter, and while I was away, Craig Developmental Center medical staff began issuing orders for medical care through my partners who were covering me. When I returned back, the medical staff at Craig had more or less demanded that everything be done for Joseph in regards to

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*It should be noted that this typed statement by Dr. Sanders was not in the patient's clinical record and was not among the material given to the Commission when this case was initially investigated, even though all notes to file by the Deputy Director were supposedly shared at that time. This statement was sent to the Commission in January 1986 in response to a request by the Commission for more information.

> aggressive medical treatment. After discussions with the Deputy Director of Health Services of Craig Developmental Center, I had to tell them that I honestly could not do the maneuvers that they were ordering me to do because, I felt that Joseph should not be subjected to any further intervention nor invasive medical care. The Deputy Director of Health Services' opinion on this was that everything possible should be done despite the wishes of the patient's relatives because the patient was still under the auspices of the State. It is my opinion that the same argument can be given to the institution of aggressive treatment in these people and that I do not feel that the State or anyone else has the right to institute the sorts of treatments [sic] just because the patient cannot respond to these issues or make a decision himself.

When the Commission interviewed Dr. Henry, he confirmed his belief that Craig officials "forbade" the Bethesda physicians from withholding antibiotic therapy. Dr. Henry stated that, due to the bureaucracy intervening in the medical care of a patient, he believed Craig was "forcing Joseph to live in constant misery." Dr. Henry stated: "Joseph's quality of life was agonizing."

TRANSFER TO GENESEE HOSPITAL

March 15, 1983: Craig Developmental Center administrators had discussed the transfer of Joseph Kirsh to Genesee Hospital with Dr. Charles* of Genesee Hospital several days earlier. Dr. Charles, who is an internist and specialist in infectious disease medicine, when interviewed, observed that

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*A pseudonym.

he agreed to take the patient, but noted there was no bed available. Two days later, without the approval of Dr. Charles, Craig administrators had the patient transported via ambulance to the Genesee Hospital Emergency Room. When seen in the Emergency Room, he was admitted and Dr. Charles was notified. When the Commission interviewed Dr. Charles, he stated that Joseph Kirsh arrived in the emergency room in "moribund, gravely ill condition."

The emergency room record at Genesee Hospital indicates an admission diagnosis of:

> Severe decubiti, necrotic; malnutrition, dehydration, history of GI bleed, microcytic anemia, seizure disorder, possible left lower lobe pneumonia, possible urinary tract infection.

The admitting medical resident described the patient as:

> Cachectic...severe contractures...hiccoughs ..severe wasting of muscles...left ankle ulcer with tendon showing...bilateral necrotic ulcers (about 15 centimeters in diameter) confluent to sacral ulcer.

On the day of admission, Mr. Kirsh was seen by a plastic surgeon, Dr. Reed,* regarding his decubitus ulcers.

A resident's admission note stated that Mr. Kirsh "was receiving conservative care at Bethesda Hospital and is now admitted to Genesee Hospital in protective custody for more aggressive care". This resident noted that, due to the infected state of the decubitus ulcers, the patient had evidence of osteomyelitis (generalized bone infection). The

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*A pseudonym.

recommendations that were made included: culturing the various lesions, as well as culturing the blood, urine and sputum, debridement of the ulcers, a bone scan, dietary consultation, and a feeding tube "if intake is less than excellent."

Due to a large amount of bleeding from the right decubitus site, a surgical resident was called to see Mr. Kirsh at approximately midnight on the night after his admission. He estimated the loss of approximately one pint of blood. The resident applied direct pressure on the wound for 10-20 minutes and described the bleeding as coming from multiple sites, plus "two small arterial pumpers." He placed some sutures within the ulceration and applied gentle pressure dressings.

March 16, 1983: Dr. Charles saw Mr. Kirsh and noted "the major problem we are faced with is management of the longstanding decubitus ulcers in a malnourished, chronically debilitated individual." Nurses' notes indicate that Betadine dressings were done on the "deep large ulcers on sacrum and feet," and that they were being irrigated with hydrogen peroxide and water. The sacral decubitus ulcers were noted to be bleeding a large amount. Appetite was termed "fair."

March 17, 1983: Dr. Charles wrote:

> ...as discussed with Dr. Reed, once patient stabilized, amputation of both limbs is the only

> solution utilizing the skin and muscle as graft material for the sacral decubiti. (Dr. Charles' emphasis). I have spoken with the Deputy Director of Health Services of Craig Developmental Center and she concurs with our plan.

A resident recorded: "cultures of the patient's hip lesion yielded proteus bacilli; ankle cultures yielded staphlococcus aureaus and anerobes; the left heel culture yielded pseudomonas and coliform; and the right heel showed proteus, pseudomonas and others." In addition, a nurses' note observed: "purulent drainage oozing from the patient's penis around the Foley catheter."

March 18, 1983: A nasogastric feeding tube was inserted through Mr. Kirsh's nostril and into his stomach, so that high calorie feedings could be given in an effort to improve his nutritional status. A 16 gauge 8-inch catheter was placed in the patient's right internal jugular vein, for the purpose of keeping an open venous line with which to give the patient fluids and intravenous antibiotics. Regular intravenous lines were becoming difficult, if not impossible, to insert in the patient's veins. The patient was given several units of packed red blood cells to counteract his anemia and blood loss through his decubitus ulcers. His periodic hiccoughs had returned.

March 19, 1983: Dr. Charles wrote the following:

> ...discussed with Dr. Brown* proposed therapy of bilateral amputation and grafting. We will need a

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*A pseudonym.

> court order signed by Dr. Reed and myself. Patient's sister called me about situation--informed (her) patient is critical. (All emphasis is Dr. Charles').

March 21, 1983: A nurse recorded a grand mal seizure and noted "hiccoughs continue. Good eye contact. Seems to understand what is being said."

March 22, 1983: Dr. Charles had photographs taken of Joseph Kirsh's various decubitus ulcers. The plastic surgeon, Dr. Reed, recorded "new areas of necrosis on both buttocks...." and noted that Mr. Kirsh would require "bilateral total thigh removal with removal of both femurs." Dr. Charles charted a plan for possible additional surgery when he wrote:

> ...will ask Dr. Melen* to see regarding general surgical situation. ? Colostomy to divert fecal stream from incontinent patient. Also have asked orthopedic opinion from Dr. Hart.*

Dr. Melen, a general surgeon, saw the patient and concurred with Dr. Charles that the construction of a sigmoid colostomy would be the "surest way to prevent infection of surgical wound after grafts of the decubitus ulcers." He also noted that such a colostomy would also "greatly facilitate nursing care", and his note ended with "would schedule him at your convenience if you agree" (emphasis added).

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*A pseudonym.

The patient was weighed on bed scales and noted to be 68.1 pounds. (Mr. Kirsh was approximately 5' 8" tall.) The amount of Ensure feedings was increased.

A neurologist, Dr. Xavier,* examined Mr. Kirsh and recorded "signs of spastic quadriplegia with longstanding flexion contractures and decubiti. Hopeless for functional life. Physical therapy could possibly overcome contractures."

March 23, 1983: The orthopedic surgeon, Dr. Hart, saw the patient and a gastroenterologist also examined him regarding his nutritional status. Several blood tests were ordered, a 24-hour urine test and a 72-hour calorie count to establish caloric needs.

Dr. Charles wrote:

> ...patient is in negative nitrogen balance which would make surgical intervention a great risk. On the other hand his infection is aggressive. If indeed, he cannot, through alimentation, turn into a positive nitrogen balance state--would feel that high risk of surgery and proposed ultimate plan for amputation would kill patient. Will rediscuss with Dr. Melen and Reed [surgeon and plastic surgeon].

March 24, 1983: It was noted that Thorazine continued to be given for hiccoughs and, as noted in the past, did not give the patient relief. A psychiatric consultation also occurred, in which the psychiatrist, a Dr. Benjamin,* noted

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*A pseudonym.

a total inability to communicate with the patient. He concluded:

> Patient obviously unable to consent to, or refuse, any care offered to him or necessary for him. If surgery is contemplated, I am not sure that a court order is necessary. If he is indeed a ward of the State, permission should be obtainable from the director of Craig Developmental Center. (Emphasis added.)

The psychiatrist then noted "I would support his receiving whatever care is deemed necessary and appropriate by his Genesee Hospital physicians."

A nurse's note described the current treatment of the decubiti as Betadine soaked fluffs packed into the decubiti and covered with elastic stockings. Another plastic surgeon, Dr. Royal,* saw the patient and wrote his concurrence that the only sure way of closing the open wounds would be to "perform bilateral thigh flaps with amputation of both lower extremeties." He also charted "suggestion of a colostomy is also certainly reasonable."

Another nurse recorded: "eye response to verbal stimuli and hand grasps in response to pain. Patient said 'hello' today. Has very bad hiccoughs. Occasionally moans."

March 28, 1983: Dr. Charles wrote in the hospital record:

> problem, of course, is if we consider surgical intervention, could he withstand:
>
> a.) A colostomy, with a post-operative period of nothing by mouth would be a problem in nutrition. Then definitive procedure to follow.

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*A pseudonym.

> b.) bilateral amputation and graft would also have consequences of nutrition.
>
> At this point, this would be most aggressive until we get into positive nitrogen balance.

Other notations indicate that at times Mr. Kirsh had pulled out both his nasogastric tube and his intravenous CVP line, necessitating their being re-inserted.

March 30, 1983: Mr. Kirsh developed a high fever, which Dr. Charles recorded was "clearly wound sepsis." He also noted "prognosis grave." The patient was now receiving three different intravenous antibiotics.

March 31, 1983: Two units of packed red blood cells were given. Dr. Charles wrote:

> Situation grave. He is in no shape to do surgery at this point. Despite aggressive antibiotics, fear the original plan would be dangerous since he would not survive surgery at this point.

April 1, 1983: Dr. Charles noted that Mr. Kirsh's fever was down, his white blood count had fallen from 42,400 to 32,900 (normal is 5,000-9,000) and charted "will reassess for surgery next week but it still appears that high risk is unchanged." A resident recorded that recent wound cultures "reveal a markedly resistant group of gram negative bacilli, especially Klebsiella."

April 4, 1983: Dr. Charles wrote in the record that he had discussed the situation with the Deputy Director of Health

Services at Craig Developmental Center, but did not comment on the substance of the discussion; he only recorded that:

> At this point, infection is controlled with antibiotics. He does have resistant organism. The risk of sepsis can recur since we have open wounds with debrided tissue. A suitable plan for prevention, since patient's both limbs are functionless and contracted, is surgical intervention with:
>
> 1) colostomy--to direct fecal stream;
>
> 2) bilateral amputations--after colostomy maintained with grafting of buttock wounds with patient's own tissues from lower extremities.

Dr. Charles' note continued, indicating he had "discussed overall situation and emergent nature of making a decision for surgical intervention with the Deputy Director at Craig Developmental Center" and that "permission for above plan reviewed and placed in record."

Dr. Charles signed this progress note and indicated beneath his signature his specialties of "Infectious Disease" and "Internal Medicine." Dr. Reed, plastic surgeon, signed beneath Dr. Charles's signature and Dr. Melen, general surgeon, also signed the note.

A nurse recorded that she was "present in room when personnel from Craig Developmental Center and Dr. Charles discussed possible patient surgery. Craig appeared to agree surgery necessary at this time." (emphasis added).

The Deputy Director of Craig Developmental Center wrote a note to the file on this same day, describing a meeting at

Genesee Hospital between himself, the Deputy Director of Health Services of Craig Developmental Center, two Mental Health Information Service (MHIS) respresentatives and Dr. Charles. The Deputy Director recorded Dr. Charles' medical opinion that: "Joseph's surgery was 'extremely necessary.'" Noting the lack of response to antibiotics, the Deputy Director wrote:

> This author in concert with the Deputy Director of Health Services and an MHIS representative agreed to authorize surgery in two stages. One to include colostomy and re-direction of the fecal stream. Second stage to include bilateral amputation of the legs and subsequent plastic surgery.*

The surgical consent form prepared by the Genesee Hospital in this case contained both errors and ommissions**.

The planned surgical procedure, as identified in the completed consent form, was described as follows:

> colostomy; bilateral amputations with autography.
>
> [Amputation of which extremeties or the extent of the amputations were not stated].
> [Autography refers to making graphs from the patient's own skin.]

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*When in January 1986 the Commission requested additional information of MHIS in attempting to clarify their role in this case, the MHIS noted, at that time, that this statement in the clinical record by the Craig Deputy Director was not accurate. The Deputy Director subsequently corrected his statement and acknowledged that the MHIS has no authority to "authorize surgery.

**See discussion, infra, pp. 45.

The form also reaffirmed that the condition and planned procedures have been well-explained and discussed by the unnamed surgeon. Consent is specifically included on this form for anesthesia and medications. The form concludes with bold face lettering: I HAVE READ THIS FORM. I UNDERSTAND WHAT IT MEANS AND IT IS ACCURATE.

April 5, 1983: The Deputy Director of Craig Developmental Center recorded that he spoke with Mr. Kirsh's sister and reassured her, in answer to her query, that "no external life support systems were intended to be used, " and that the sister expressed her intention to pray for Joseph's death during surgery, to put an end to his suffering.

The Deputy Director of Craig Developmental Center contacted this Commission with the request that the Commission provide assistance in assuring that an autopsy would be done if the patient died. Specifically, the Deputy Director wanted the Commission to discuss the case with the Monroe County Medical Examiner. The Commission requested that the specific areas of concern to Craig Developmental Center be put in writing prior to contacting the medical examiner.

April 6, 1983: Joseph Kirsh was readied for colostomy surgery and for the placement of a jejunal feeding catheter,* in order to decrease the risk of aspiration.

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*The jejunostomy, an invasive procedure, was done in conjunction with the colostomy. There was no notation on the operative consent form stating that a jejunostomy would also be performed.

The colostomy and jejunostomy were performed and Joseph was described post-operatively as being unresponsive, although in the afternoon he did move his head and eyes.

POST OPERATIVE CONDITION AND TREATMENT

On April 9, jejunostomy feedings were begun. A gastroenterologist examined the patient and noted that there was some gastrointestinal bleeding. Over the next eight days, Mr. Kirsh's condition continued to deteriorate and, on April 17, Dr. Charles wrote in the record "we are in desperate situation." On April 19, the Director of Craig Developmental Center wrote to the Commission, as requested by the Commission on April 4, 1983, specifying his desire that an autopsy should be done when this patient died, for three reasons:

1. Unexplained gradual mental and physical deterioration of several years duration.
2. Intractable hiccoughs.
3. Unexplained chronic GI bleeding.

The Commission later discussed the case with the Monroe County Medical Examiner, who agreed to perform an autopsy, if and when Mr. Kirsh expired.*

Mr. Kirsh's condition continued to worsen and, on April 21, 1983, Dr. Charles recorded that a chest x-ray

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*When the patient died, the sister did in fact agree to an autopsy, and it was done at the Genesee Hospital.

showed a possible atelectasis (collapse) of the lung. Dr. Otto,* a pulmonary consultant, charted that he agreed with Dr. Charles, that the patient required a bronchoscopy because of "total left lung atelectasis."** The bronchosocpy was performed and the findings were severe tracheobronchitis, with a large amount of purulent secretions present and left lung atelectasis (collapse).

On April 29, 1983, jejunostomy feedings were resumed using a special high protein feeding formulated for cachetic (wasting) patients. However, on May 6, 1983, these feedings were discontinued when it was noted that material suctioned from the patient's trachea resembled the feeding liquid.

On May 14, 1983, Mr. Kirsh's breathing was described as "extremely difficult" and a chest x-ray revealed "probable right aspiration pneumonia." Dr. Haggerty noted that "until aspiration propensity is corrected, we cannot tube feed." The following day, a urological consultation was requested. It was noted that the patient's penis and scrotum were swollen. At 7:45 p.m., it was noted that the patient was "very dusky" and suctioning yielded frothy brown sputum.

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*A pseudonym.

**A bronchoscopy is a procedure whereby a bronchoscope, an instrument for visualization of the interior of the bronchus, is inserted through the oropharynx down into the trachea. The Commission requested a copy of the consent form issued for the bronchoscopsy procedure and was told no consent form was used.

The nurse began CPR using an ambu bag. An on-call resident saw the patient and recorded, in a note labeled 8:20 p.m.:

> Patient found unresponsive, without pulse or spontaneous respirations. Resuscitation attempt begun at 7:50 p.m. with intubation and manual respirations. EKG showed a flat line.

This resident gave Mr. Kirsh several emergency drugs via injection and recorded "pronounced dead at 8:15 p.m. by myself." The patient's sister was notified and gave permission for an autopsy.

AUTOPSY RESULTS

The autopsy was done at Genesee Hospital by the hospital pathologist on the day following the patient's death. The final autopsy report, a lengthy and detailed twelve-page document, was received by the Commission seven months later, in December 1983, and can be summarized as follows:

> The final anatomical diagnoses were:
>
> bilateral (right greater than left) aspiration pneumonia with granulomas and abscess formation and left pleural effusion (2,000cc).
>
> multiple decubitus ulcers of both hips, sacrum and both ankles.
>
> colostomy of descending colon with dilatation of ascending colon.
>
> feeding jejunostomy.
>
> acute and chronic esophagitis with ulceration.
>
> flexion contractures both legs and both arms (left greater than right).
>
> testicular atrophy.

In the "clinical pathological correlation" section of the autopsy report, the pathologist noted that the autopsy showed the apparent results of the injuries sustained by Joseph Kirsh when he fell out of a window at two years of age. The report stated that there were contusions of both frontal lobes. The autopsy revealed the anatomical correlation between Joseph Kirsh's deterioration, from an active moderately retarded young man to one who, in his mid-years, showed mental and physical deterioration due to communicating progressive hydrocephalus.*

The pathologist's report stated that:

> Most certainly the deterioration from IQ of 52 to IQ of 20 and the change from ambulatory to severe spastic immobility were the result of the marked progressive cerebral damage from the massive hydrocephalus.

The autopsy report speculated that Joseph Kirsh experienced marked brain swelling secondary to his childhood head injury, and that the herniated temporal lobe uncus produced pressure on the right posterior cerebral artery, occluding the flow of cerebrospinal fluid, which resulted in a right occipital lobe infarction. Findings on autopsy, it was noted, would be those expected after long-term recovery from such an infarction.

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*Hydrocephalus is a condition in which there is increased accumulation of cerebrospinal fluid within the ventricles of the brain.

Although the pathologist observed that the patient had hiccoughs since 1981, no etiology for this was found on autopsy. The patient's acute and chronic esophagitis with ulceration was recorded, and the pathologist commented that these findings could be "possibly secondary to feeding tube trauma and reflux of gastric contents." It was further charted that there was "evidence of aspiration pneumonia, with foreign material evident in pulmonary granulomas and abscesses. Pneumonia was most probably the cause of death in this patient."

FINDINGS OF CRAIG DEVELOPMENTAL CENTER, MORTALITY REVIEW COMMITTEE

The Mortality Review Committee of Craig Developmental Center discussed two issues: (1) The conservative and then aggressive treatment provided this patient at Bethesda and Genesee Hospitals, respectively, and; (2) why there was a lack of a neurological work-up for this patient by Craig Developmental Center.

Regarding the first issue, the minutes noted that:

> After a prolonged stay at the Bethesda Hospital, it was decided by his attending physician to do only palliative therapy...Craig Administration was opposed to the decision...and numerous attempts to make the physician resume active medical treatment...were made but failed. Because his condition was deteriorating rapidly, Craig Administration decided to seek help from another community hospital which resulted in the transfer of Joseph to Genesee Hospital under the care of the infectious disease specialist.

The minutes continued:

> The Mortality Review Committee also acknowledged the fact that, because there are no guidelines from the Office of Mental Retardation and Developmental Disabilities as to how far to go in trying to save a client's life, it has created a lot of confusion and antagonism from community physicians towards the State physicians and State administration because they feel that to interfere in the management of a patient under their care is unethical; (emphasis added).

The Mortality Review Committee then wrote as a recommendation:

> There should be a clear policy and/or guidelines as to who has the authority to intervene when there is a disagreement in the management of a client between the treating community physician and state-employed physician. Do the living relatives, who are not the legal guardians, have the authority to make the decision to withhold treatment?

As to the lack of a neurological work-up and follow-through at Craig Developmental Center, the Committee noted that Joseph Kirsh had gradual deterioration of "motor functions and level of functioning." The report observed that, although he "had been followed by a neurologist," (no dates were stated) there "is no record of any further neurological workup done to investigate the cause of his deterioration," but does not explain this.*

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*The Commission requested Craig Developmental Center to provide copies of all neurological consultations on Joseph Kirsh. None were found.

The Mortality Review Committee, however, did recommend that:

> When a physician has a client with deteriorating neurological functioning, it is recommended that this should be pursued since non-invasive procedures are now available to rule out any organic cause of the problem.

MENTAL HYGIENE MEDICAL REVIEW BOARD REVIEW

The Mental Hygiene Medical Review Board reviewed this case at its November 3, 1984 meeting and determined the cause of death of Joseph Kirsh to be:

> cachexia (wasting) related to long-term malnutrition; extensive decubitus ulcerations; bilateral aspiration pneumonia; status post-colostomy in preparation for bilateral amputation of the lower extremeties; old brain injury incurred in fall from window at age two, followed by progressive and undiagnosed hydrocephalus which caused the patient's deterioration.

The Board questioned the reasonableness of the decisions to aggressively treat Mr. Kirsch, including the colostomy surgery and the proposed bilateral amputations of his legs. It noted that Mr. Kirsh's poor physical condition resulted largely from years of neglect, poor nutrition and little physical activity and therapy, as well as a continuing deteriorating mental condition over the years that went undiagnosed, and therefore untreated. The Board noted that the unusual aggressive policy of medical and surgical treatment, absent a comprehensive medical evaluation, was inappropriate. The Board also found that Craig's decision to operate on Mr. Kirsh had run counter to the expressed wishes of his next-of-kin.

FINDINGS

1. THIS PATIENT WHILE IN CRAIG DEVELOPMENTAL CENTER DETERIORATED FROM AN AMBULATORY, MODERATELY RETARDED YOUNG MAN TO A SEVERELY RETARDED, CONTRACTED, MULTIPLY-INFECTED BED PATIENT OVER THE COURSE OF A FEW YEARS; HOWEVER, THERE WAS NO CONCERTED EFFORT TO ATTEMPT TO DIAGNOSE AND ADDRESS THE CAUSE OF THIS DETERIORATION.

On autopsy it was shown that hydrocephalus was responsible for the change in the patient's mental status over the years of his stay at Craig Developmental Center. The Medical Review Board noted that a neurosurgical procedure could have prevented this deterioration by placement of a shunt to prevent excess spinal fluid in the ventricles. The Board lamented the fact that during these years, when the patient's deterioration was obvious, there were no neurological or neurosurgical consultations, EEG's, skull films or CAT scans done in an effort to find the etiology of the patient's condition.

Mr. Kirsh's deterioration is shown in the Craig Developmental Center record by the marked difference in the results of the annual psychological tests, as well as the obvious change in the patient's physical condition and mobility capability. However, the only comments by physicians regarding this deterioration were periodic documentation the patient's declining physical status.

Recommendations made by psychologists, calling for behavioral and activities intervention to offset the patient's deterioration, do not appear to have been addressed by any other members of the treatment team or the facility, nor did the patient receive the special stimulatory therapy as suggested by the psychologist, since he was determined to be "medically exempt" from programming mandates. Similarly, the notes by the physical therapist were not integrated or considered with the other discipline notes, and there is no evidence of a team effort to implement simple, but necessary, daily physio-therapeutic activities in an effort to deter further physical regression.

Although there is a noted objective in the treatment plan in May of 1982 for physical therapy three days per week, there is a further unexplained note that physical therapy is being "discontinued due to total medical exemption." There is a treatment team note of January 1983 indicating that some members of the team believed that Mr. Kirsh should receive "2 hours of leisure time per week" rather than "full medical exemption from programming." The team members present (nurse, social worker, recreation therapist and physical therapist) also noted they would "like a physician to make a referral to the adaptive equipment department for a proper fitting wheelchair." There is no indication that this was done or that anyone

assumed the responsibility to coordinate the various recommendations or statements of need.

2. A LACK OF CLEAR OMRDD POLICY OR GUIDELINES CONCERNING (i) THE DECISION TO PURSUE A COURSE OF AGGRESSIVE OR PALLIATIVE CARE, AND (ii) THE RESPECTIVE ADVISORY ROLES AND DECISION-MAKING RESPONSIBILITIES OF DEVELOPMENTAL CENTER MEDICAL ADMINISTRATION, PRIVATE TREATING PHYSICIANS, AND NEXT-OF-KIN RELATIVE TO MEDICAL TREATMENT, CREATED CONFUSION AND DISAGREEMENT AMONG THE INTERESTED PARTIES AS TO THE APPROPRIATE CARE AND TREATMENT OF MR. KIRSH.

Throughout Mr. Kirsh's stay in Bethesda Hospital, there was confusion and often disagreement among the hospital treating physicians and the Craig Developmental Center medical care staff and administration regarding the appropriate care and treatment Mr. Kirsh should receive. The hospital treating physicians believed that the patient was in a terminal condition and, accordingly, should receive less than aggressive (palliative) treatment, while the Craig medical care staff and administration believed that aggressive care of Mr. Kirsh was both appropriate and essential. What seems clear from the hospital records and communications between representatives of the two facilities is, not only a lack of agreement as to the seriousness of Mr. Kirsh's condition, but, more basically, an absence of criteria to be used to determine the condition and quality of life of a severely mentally disabled patient. Furthermore, there was an absence of clearly written

OMRDD policy as to whether palliative treatment is ever appropriate and, if so, under what conditions. Finally, this case presents a clear example of the different interpretations that medical professionals can and will give to the concepts of "aggressive treatment," "palliative" or "conservative treatment" and the need for clarity when such terms are used.

This case also graphically illustrates the absence of clarity and direction in OMRDD regulations, policies, and procedures regarding the roles and responsibilities of family members, hospital treating physicians, and State facility medical and non-medical administrators in determining the care and treatment to be provided to a patient in an outside medical facility. While the Craig Developmental Center administrators contended, in their communications with Bethesda Hospital treating physicians, that Joseph Kirsh's sister had no legal authority to authorize palliative care for her brother, OMRDD policies authorize a patient's next-of-kin to consent to a major medical procedure when the patient is incompetent.* Clearly, the general care and treatment of patients must be initially vested in the treating physicians. What are the roles of State facility representatives to monitor such

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*See further discussion on this point, infra, pp. 41-42.

care and treatment? When, and under what circumstances and protocol, should there be intervention? What role, if any, should the immediate family (spouse, parent, adult child) have with respect to consultation or advice relative to the general care and treatment of an incompetent patient? When sharp differences of opinion occur, what is the obligation of a State facility to seek judicial resolution of the question of what is in the best interest of a mentally incompetent person for whom there is no clearly authorized surrogate decision-maker? Finally, this case illustrates the further confusion as to what role next-of-kin, who are not immediate family members, have in providing advice or being consulted regarding the care and treatment of such a patient.

3. THERE WERE A NUMBER OF QUESTIONABLE DECISIONS IN THIS CASE INVOLVING CONSENT FOR MAJOR MEDICAL PROCEDURES AT BOTH BETHESDA AND GENESEE HOSPITAL.

A. AN ENDOSCOPY WAS ATTEMPTED THREE TIMES AT BETHESDA HOSPITAL, BASED ON A TELEPHONE CONSENT FROM A CRAIG DEVELOPMENTAL CENTER ADMINISTRATOR, WITHOUT ANY INDICATION IN THE RECORD THAT THE PROCEDURE WAS AN EMERGENCY.

B. A BRONCHOSCOPY WAS PERFORMED IN A NON-EMERGENCY SITUATION AT GENESEE HOSPITAL WITHOUT ANY CONSENT.

C. MOST IMPORTANTLY, THE METHOD, FORM, CONTENT, TIMING AND CONSIDERATIONS GIVEN TO THE GRANTING OF EMERGENCY

CONSENT FOR A COLOSTOMY AND BILATERAL AMPUTATION AT GENESEE HOSPITAL WERE OF QUESTIONABLE LEGAL VALIDITY.

It is the law of this state that non-emergency major medical procedures, especially surgery, cannot be performed without the informed consent of the patient. If the patient is determined incompetent to make such a decision, someone legally authorized to act on his or her behalf,* such as a spouse, parent, adult child or a court of competent jurisdiction, may authorize the procedure.**

In addition to the law and regulations, the Office of Mental Retardation and Developmental Disabilities has issued Policy and Procedure Directives.*** It is clear that for

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*NY Public Health Law §2504 and §2805-d; see also Schloendorff v. Society of NY Hospitals, 211 NY 125, 129 (1914).

**14 NYCRR §27.9(b) provides:

If a patient is 18 years or older, but in the opinion of the chief of services does not have sufficient mental capacity to give consent, authorization for the procedure in question must be obtained from the spouse, a parent, an adult child, or a court of competent jurisdiction. Nothing in this section shall prevent the director from giving consent to surgical procedures under emergency conditions where there appears to be significant danger to life or limb of the patient if the procedure is delayed.

***NYS DMH Policies and Procedures for Mental Retardation, No. 7.16.16. (May, 1977). This directive states that: "parents, next-of-kin, or guardian" may routinely consent for persons under 18 years old and incompetent patients over 18 years of age. The term "next-of-kin" is normally and legally defined as the next closest relative, and thus could well mean a person other than a "parent, spouse or adult child" permitted pursuant to regulations; see Mtr. of Barbara C., 101 A.D.2d 137, 474 N.Y.S.2d 799, leave to appeal granted 63 N.Y.2d 601 (1984).

incompetent patients, surrogate decision-making can only be exercised by a person with legally recognized authority or directly by a court of law. Nowhere in law or regulations is a facility director authorized to give consent in a non-emergency situation. The express exception is that which allows the facility director to act in "emergency situations," which is defined in the regulations as "when significant danger is posed to life or limb of the client."

In the context then of the statutory law, regulation and policy and procedures directives, the decision to attempt to perform an endoscopy on Joseph Kirsh on January 28, 1983 at Bethesda Hospital without obtaining consent was clearly improper. The record does not indicate an emergency situation and, accordingly, the Craig Developmental Center administrator who gave telephone consent to proceed did so improperly. Similarly, the record indicates no consent was obtained from anyone for the bronchoscopy performed at Genesee Hospital on April 21, 1983, and neither the record, nor the nature of that procedure, indicate that the procedure was utilized in an emergency situation.

More complex, however, is the question of the legal validity and the appropriateness of the consent given for the colostomy and bilateral amputation, under what was considered by Genesee treating physicians, Craig Developmental Center administrators and Mental Health Information Service representatives as warranted in an "emergency situation." The actual emergency nature of the presenting situation is questionable for a number of reasons.

First, the operation had been contemplated and discussed for several weeks among both treating and consulting hospital physicians and Craig administrators. Thus, on March 17, 1983 the Genesee Hospital records note a decision by the treating physician "once patient stablized" that a bilateral amputation of both legs would be scheduled. This decision was agreed to by a consulting surgeon, as well as the Deputy Director of Health Services at Craig Developmental Center. Again, on March 19 Dr. Charles, the primary treating physician, noted in the record a discussion with Dr. Brown regarding bilateral amputation and grafting. Interestingly, Dr. Charles also wrote in the record, "We will need a court order signed by Dr. Reed and myself" (Emphasis is Dr. Charles'). A March 22 medical record entry indicates a decision to do a sigmoid colostomy. The consulting surgeon who made the recommendation suggested that Dr. Charles schedule Mr. Kirsh for such surgery "...at your convenience if you agree". A confusing and perplexing medical record entry is noted on March 24, 1983 when, after confirming Mr. Kirsh's inability to consent to surgery, a consulting psychiatrist notes:

> ...if surgery is contemplated, I am not sure that a court order is necessary. If he is indeed a ward of the State, permission should be obtainable from the director of Craig Developmental Center.

Again, in medical record entries on March 28 and 31, it is clear that surgery is contemplated if Joseph Kirsh's

condition improves enough to permit surgery. The actual decision to operate was made by the treating and operating physicians, Drs. Charles, Reed, and Melen, on April 4, when the patient's condition improved, in that his infection was deemed under control. A notation in the medical record of Joseph Kirsh indicated that the three physicians "discussed overall situation and emergent nature of making decisions for surgical intervention with the Deputy Director from Craig. At this point surgical intervention is extremely necessary." It was on that date, under a premise that the surgery was being performed in an emergency situation, that consent forms were signed by the Craig Deputy Director. In fact, in spite of the determination of an emergency situation, the surgery was not performed until two days later, April 6.

Secondly, the bilateral amputation of Joseph Kirsh's legs, which was one of the two procedures for which consent was obtained, was not to be performed until the patient sufficiently recovered from the quite separate procedure of the sigmoid colostomy. Under the best of circumstances, this proposed bilateral amputation could not have been performed for a number of weeks, and clearly was dependent upon the patient's successful post-operative response from the colostomy. Yet, both procedures, very separate in nature and time, were considered on the same form and were reviewed and approved in the context of an "emergency situation."

Finally, the surgical consent form actually prepared by Genesee Hospital in this case was deficient in a number of ways. For example, the form:

a) was undated;

b) the line for the date was written: "4/ ___" (which also might indicate the actual date for the "emergency" procedure was undecided);

c) the line for "doctor's signature" was signed by the infectious disease specialist, not the surgeon who was to perform the colostomy and, in fact, no surgeon was identified on the form (even though the standard form language on the hospital's standard from states that the condition and planned procedures have been discussed by the unnamed surgeon);

d) the completed form did not identify which extremities were to be amputated or the extent of the planned amputations;

4. THE "DO NOT RESUSCIATATE" (DNR) ORDER AT BETHESDA HOSPITAL WAS IMPROPERLY ISSUED BY TELEPHONE BY THE TREATING PHYSICIANS, WITHOUT PRIOR CONSULTATION WITH THE NEXT-OF-KIN OR CONSULTATION WITH CRAIG DEVELOPMENTAL CENTER ADMINISTRATORS. THE BETHESDA HOSPITAL DNR POLICY WAS ALSO INADEQUATE.

The treating physician gave a DNR order as to Joseph Kirsh inconsistent with the Hospital DNR policy, in that

the order was given by telephone to a nurse, who then noted it in the patient's record. The physician also did not contact the patient's next-of-kin (his sister) to discuss the order until the following day, and it was only then that he documented that conversation and apparently countersigned the DNR order previously noted in the record.

Furthermore, in spite of the fact that the treating physician knew that Joseph Kirsh was a patient from Craig Developmental Center, he apparently made no attempt to contact the Craig administration to consult with them in giving the DNR order. In fact, Craig administrators apparently were not aware of the order until more than a week later.

It is also noted that the then existing Bethesda Hospital DNR policy inadequately provided for the conditions under which a DNR order could be given and implemented. Bethesda Hospital has since been closed.

CONCLUSION

The Commission recognizes the inherent difficulties that confront State institutions that must make medical care decisions on behalf of incompetent residents, who have no personal representative legally able and willing to make such decisions on their behalf. By opting for conservative treatment, the institution may subject itself to severe criticism for failing to take all appropriate measures that perhaps an involved family or guardian might demand. Yet,

opting for aggressive medical treatment in all cases as a general policy has its own pitfalls, as poignantly illustrated in this case. Such a policy may result in prolonging a painful death rather than preserving the dignity of life.

The formulation of level of care and treatment guidelines for facility clinicians employed by the State would be a great improvement over the current situation. Guidelines should facilitate intelligent and sensitive decision-making, based on the relevant facts and circumstances of each individual case, taking into consideration the opinions of treating physicians, as well as available family members. Such guidelines also should take into consideration situations, such as in this case, where an incompetent State facility resident is treated in other than a State medical facility, and by private treating physicians who must be informed of State guidelines and treatment approval processes. This would help in meeting the best interests of the clients.

Once a treatment plan is developed and implemented in conformance with such guidelines, facilities should, nevertheless, ensure that legal requirements for obtaining informed consent for major medical procedures are followed. Legal advocates, such as Mental Hygiene Legal Services, should ensure that, where the patient is incompetent to make

an informed decision, an appropriate, legally-authorized surrogate decision maker makes such a decision on his behalf. Here, too, existing State procedures appear inadequate and need to be revised to make clearer who specifically can provide consent when the patient is incompetent to make an informed decision, the procedures for obtaining such consent and those limited circumstances where a true emergency situation enables the caregiver itself to give the consent.

The unfortunate case of Joseph Kirsh illustrates a number of problems with the existing consent process. Not the least of which is that situations may exist where an incompetent patient, without a legally recognized surrogate who can provide consent, is deemed by his caregivers to be too ill for an operation and, accordingly, no action is commenced to obtain court approval of a major medical procedure, which may be needed when and if the patient's condition improves. In such a situation, if the patient's condition does <u>improve</u>, the caregiver can arguably authorize a major medical procedure on the premise that it is an emergency situation, because the patient's condition is too fragile to await court approval before the procedure is undertaken. Clearly, such a result was not intended by the statute and regulations, which were meant to assure the patient an objective third party determination as to whether any major medical procedure, in fact, is in the best interests of the patient.

Finally, one would hope that legal advocates, such as Mental Hygiene Legal Services, would be especially sensitive to such situations and insist upon the following of the legal consent provisions in such a manner as to assure, for non-emergency situations whenever possible, court approval where no legally recognized surrogate exists. The legal requirements as to consent must be followed in spirit as well as by the letter.

RECOMMENDATIONS

1. OMRDD should clarify, by specific statements of policy and guidelines, who should be consulted with respect to general medical care decisions, not involving major medical treatment of surgery, relating to incompetent clients. The policy should particularly address the role of non-parent or non-spouse family members in such situations, and the role of treating physicians in non-state-operated medical facilities in the decision-making process.

2. OMRDD should clarify its regulations and policies regarding who has the right to consent to non-emergency major medical procedures on behalf of an imcompetent client. Policy guidelines also should be developed to relate to those circumstances under which a court order should be sought to authorize a major medical procedure, in the absence of a legally recognized surrogate, and to define what constitutes emergency situations.

3. OMRDD should provide training for developmental center medical and administrative staff regarding legal requirements and policies for making medical care decisions, especially decisions to perform major medical procedures.

4. OMRDD should develop a process by which its regulations, policies and guidelines, relative to who should be consulted and by whom regarding medical care decisions, and who has the right to consent to major medical procedures for an incompetent client, are made known to non-state-operated medical facilities and treating physicians.

5. Craig Developmental Center should evaluate its treatment planning process to assure that periodic multi-disciplinary treatment reviews of all clients actually address all of the needs of the client, and assess any changes observed by any team member. These reviews should include participation of the medical and psychology departments and should assess and follow though on all issues relating to the client's needs. The treatment plan thus developed should clearly state the methodology to be used to address these issues and should be implemented with a coordinated team approach.

6. A primary health care coordinator/advocate should be assigned the responsibility of coordinating the needs of each client and to follow-up on individual team members' recommendations, in order to promote attention to both the physical and psychological needs of the client.

7. The Craig Developmental Center should assess its current capacity for delivering physical therapy services to all non-ambulatory, semi-ambulatory and other clients in need of such services. Provision should be made for the delivery of such services daily on the units by nurses and aides trained in specific techniques. Such daily on-unit treatment should be augmented by the patient's participation in more intensive physio-therapy, given by physical therapists and physical therapy assistants. The preventative aspects of physical therapy should be stressed and viewed as a primary and essential service in a developmental center.